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ABSTRACT

This guidebook provides information, activities, and overheads to help educators better understand approaches and strategies toward making sexuality education more accessible to persons with developmental disabilities. Chapter 1, "How Do I Start? Where Do I Start?," discusses providing accurate, age appropriate, and useful sexuality education. Chapter 2, "Why Do I Do This?," examines effects of sexuality education for people with developmental disabilities. The following chapter, "Who Is My Audience?," provides different definitions of developmental disabilities. Chapter 4, "What Might Slow Me Down," explores barriers to effective teaching and finding out the best available learning channels. Chapter 5, "How Do We Learn What We Know," discusses adaptive activities and the difficulties that people with developmental disabilities have in adapting to new situations. The next chapter, "Why is S/He Doing That?," explains the importance of making abstract ideas more concrete. The final chapter, "What Do I Say? How Do I Say It?," provides a framework for preparing and exploring sexuality and social skills education. Activities are provided for exploring feelings, paradigms, and levels of comfort. A list of resources is included. An appendix includes an historical overview of the history of society's attitudes toward people with developmental disabilities and sexuality. Contains 15 references. (CR)

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Talking Sex!

Practical Approaches and Strategies for Working With People Who Have Developmental Disabilities When the Topic is SEX

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Talking Sex! Practical Approaches
and Strategies for
Working With People
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Sex©

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Thank you to Planned Parenthood of Tompkins County for their support and encouragement of my work; and for their continuing commitment to the importance of sexuality education for people who have developmental disabilities. Thanks also to the guy in the back of the training room who, so many years ago, offered to buy my notes at a conference in order to convince his agency of the need for sexuality education for their consumers. And thank you to Maureen, who has comforted me in stormy times, danced with me in joyous times, and always been right by my side.

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Introduction

Why a New Guide?

My presentation on "Teaching About HIV/AIDS with People who Have Developmental Disabilities" was attended by a standing-room-only crowd. It was also the first session ever offered at this particular statewide sexual health conference to focus on working with people with developmental disabilities. As I packed up my materials and chatted with a few lingering workshop participants, a gentlemen made his way to the front of the room. "Can I buy your notes?", he greeted me. Unsure of what he meant, I listened as he continued, "I have been trying to convince my agency to provide sexuality education for our consumers, and they just don't understand the need. Your presentation is just what they need to hear - so, would it be possible to get your notes? Please? I'm willing to pay anything you want for them out of my own pocket" - he took out his billfold - "Just name your price..."

The year was 1989, and although I declined this unusual offer to sell my presentation notes, I instead provided a full training on sexuality issues for the entire staff, administration and board of directors of his agency. This experience of meeting a person so committed to addressing the sexuality education needs of consumers was the original inspiration for my 1991 work *Positive Approaches: A Sexuality Guide for Teaching Developmentally Disabled Persons*. At that time, few resources were available in this field.

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Since that time, I have provided many more trainings on these issues, many times, to people (both professionals and consumers themselves) who have not had any other access to such information. I have met people who have had to take a sick day in order to have time off work to attend, people who have paid their own way when their agencies could or would not, even people who have traveled from other countries in order to obtain this information to bring back to their own land. Parents have arranged respite care and brainstormed other creative solutions in order to come to conferences, and I have received e-mail queries from all over the globe. The need for this information still exists, and the difficulties consumers and professionals have in obtaining it are specific to their unique needs - isolation, lack of resources, lack of time, limited opportunities for self-advocacy, burnout, lack of supervisory/agency support, quick staff turnover that prevents skills building, lack of advocates, small numbers of skilled professionals in the field, lack of networking opportunities...the list goes on and on.

Therefore, it's time for a new manual to address the challenges and opportunities of sexuality education for people who have developmental disabilities as we enter the 21st century. Questions and situations are more complex, as many factors face individuals with developmental disabilities and their caregivers that simply did not exist even a decade ago. A few of these are listed below:

✔ Technology and access to information have increased dramatically over the last decade. The internet has connected parents, educators, and consumers themselves, throughout the world. Assistive technologies now allow some people to communicate, expressing themselves through speech for the first time (and even choosing the sound of their own voice through computerized speech boards).

✔ Contraceptive and reproductive technology has changed. Norplant, Depo-Provera, the female condom, polyurethane condoms, and pre-packaged emergency contraception have all made their debut over the last decade. Each of these has the potential to create a

profound impact on the sexuality of people who have developmental disabilities. And, through fetal testing, some parents can now begin preparing during pregnancy for the special needs their children may have when they are born. Some therapies in women considering pregnancy have even been shown to prevent certain developmental disabilities.

✔ Medical developments and a greater understanding of health management issues of people with disabilities have extended the life span of people with some types of developmental disabilities. But these have also prompted ethical "quality of life" debates. Queries like, how to choose between developmentally disabled and non-disabled candidates for expensive organ transplants or cancer treatments, have been spurred by insurance company bottom lines. Ethical debates surround expectant parents who choose to proceed with a pregnancy after receiving genetic counseling that their fetus may be affected with developmental disabilities. The potential to be penalized or stigmatized by the medical and insurance industries for making this type of choice (that may require more intensive or expensive treatment) would have been unheard of even a few years ago.

✔ Knowledge of HIV/AIDS has grown dramatically, and so has awareness of cases of HIV in individuals with developmental disabilities. Still, few prevention efforts (or health promotion messages in general) are geared to this population. (For information on general health promotion efforts in populations of developmentally disabled individuals, see the Resource section).

✔ Body image issues have also impacted communities of individuals with developmental disabilities and their families. Pressure to physically conform to social standards of acceptable appearance affects both consumers and their families. Some families even explore the new option of plastic surgery to achieve a more "normal" facial appearance for their children with Down Syndrome and other conditions.

✔ Role models have also appeared, as a small number of television programs and movies incorporate characters with developmental disabilities into their plot, (particularly their sexual experiences and questions). A handful of advertisers spotlight individuals who have developmental disabilities as models in their television and print advertisements. And in the scientific and literary world, an accomplished and prolific author with autism, Temple Grandin, has been featured in several documentaries and newscasts. Sensationalized tabloid-style news stories of families coping with a few rarely occurring developmental disabilities have aired for the first time as well, perhaps best exemplifying the entry of at least a beginning of awareness (albeit misguided) of developmental disability into mainstream consciousness.

✔ The changing demographics of people who have developmental disabilities must be considered as well. Normalization and deinstitutionalization brought many people from large, isolated institutions into the community at large. The landscape of how and where these individuals with developmental disabilities live - and how society responds - is changing dramatically. No longer affected by antiquated medical ideas that institutions provide the optimum environment, an overwhelming majority of families raise children who have developmental disabilities themselves. This has caused schools and community agencies to have to keep up in order to serve many previously invisible individuals. Many communities are wrestling with issues that have never before had the opportunity to surface.

For example, going to the prom and playing on the football team, activities long-enjoyed by their peers, are now available for school-aged youth with developmental disabilities. Although seemingly simple pleasures, they have sparked debate regarding inclusion in a number of school districts throughout the country. Funding issues, such as the provision of specialized aides, assistive technology, and even transportation, face communities attempting to provide youngsters who have developmental disabilities with the education they are entitled to under the law. Respite care for families, and financial

and life-planning for individuals as their parents/caregivers reach older age is also a major issue.

✔ Other legislative and political landscape features have changed, too - ideas of universal healthcare (and how it would be paid for, for whom, and for what medical conditions), welfare reform, continuing dialogue about adherence to ADA regulations - all have a great impact on individuals who have developmental disabilities. Even economic factors play a role. In a time of extremely low unemployment, nearly all potential workers are utilized. If an economic downturn were to occur, would that affect employees with developmental disabilities first? Concurrently, as mechanization takes over increasing numbers of manual and repetitive tasks, how does that affect (sheltered) industries that are traditionally staffed by individuals who have developmental disabilities? Have they been trained to do a soon to be non-existent task? What are the issues of pay equity among people who have developmental disabilities? For instance, jobs like sorting recycling, counting out items to be pre-packaged, erasing and repackaging videotapes, are rapidly becoming computerized and mechanized, with little need for human labor in the process.

✔ The emerging self-advocacy movement is also a force to be reckoned with, as consumers gain more experience and skill in expressing their opinions directly to those who serve them, like: family members, caregivers, medical professionals, and legislators. A concurrent development has been the beginning public voice of adult children whose parents have developmental disabilities. Long believed to be children who would also be disabled (whether due to genetic causes or environmental and social factors), this group is soundly smashing myths and stereotypes as they make their experiences, needs, and issues known. (One example of this literature is *On Loving and Hating My Mentally Retarded Mother*, Carol Rambo Ronai, PhD. *Mental Retardation: A journal of policy, practices, and perspectives*, 35 (6), 417-432, December 1997.)

In a world in which so much has changed, however, there are still everyday reminders of how much of a struggle still remains. Taunts of "retard" and similar slurs are still tolerated in the hallways of our schools (and indeed still tolerated on our TV screens, as the host of a major network morning show recently uttered this word on-air as a put-down). Although name-calling along with other issues of diversity have long been recognized as inappropriate and unacceptable, disability name-calling joins homophobic name-calling as widespread types of disrespect that are still practiced in society, relatively free from threat of censure or consequence.

One important rationale for continuing efforts in sexual health and social skills education for people who have developmental disabilities is that when people feel good about themselves they are more likely to make healthy choices. When people lack self-esteem, they may not seek out the information or assistance they need in order to make healthy choices. In a society that already de-values them, people who have developmental disabilities are at great risk.

It is important to remember that people who have developmental disabilities come from all walks of life -- from all faiths, racial and ethnic groups, socioeconomic classes and sexual orientations. The sexual orientation of people who have developmental disabilities has long been ignored by society. But within recent years, the unique needs of gay, lesbian, bisexual, and transgender consumers have just begun to be recognized. The growing self-advocacy movement has also given voice to these consumers, who are demanding equal access to information and services that address their needs. When addressing issues of sexuality --regardless of the ability levels of your audience -- it is vital to incorporate information and educational materials that reflect *all* sexual orientations. By doing so, you will allow for each individual to relate from their own personal experience (rather than assuming a heterosexual norm). Providing a variety of information about sexual orientation also helps to create an accepting environment where sexual diversity is openly discussed. By fostering a comfortable environment for all of your participants, you will provide the best possible learning experience. Consult the Resources section for organizations and websites that provide further information on sexual orientation and gender identity.

Much ground has been covered on the topic of sexuality education and information for people who have developmental disabilities, but there is still much to be done. As we take on the challenges still awaiting us, ***Talking Sex! Practical Approaches and Strategies for Working with People who have Developmental Disabilities When the Topic is Sex***, provides information, activities, and resources for people who want to make a difference in today's world.

How to Use this Resource

What this resource is and what it isn't...

The information, activities, and overheads on the following pages will provide a foundation to help the reader better understand approaches and strategies toward making sexuality education more accessible to the person with developmental disabilities.

Updates, facts, and data on human sexuality in general (including sexual behaviors, contraception, sexually transmitted diseases, sexual orientation, gender identity, and other issues) are NOT included in this resource. Such information can be easily obtained through many sources, including your local Planned Parenthood office. Other general sexuality references are also listed in the Resources section of this guide.

What the reader will find in this guide is a lens through which to look at those pieces of sexuality information to make them relevant and useful to people who have developmental disabilities. This is a framework to use in taking sexuality information you already have, and making it more useful in work with populations with special needs; it also provides needed background when embarking upon the charge of creating an entirely new sexuality education program for people who have developmental disabilities.

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Chapter One

How Do I Start? Where Do I Start??

Questions, feelings, and fears about teaching about sexuality with people who have developmental disabilities

As the last resident boards the bus to work, the residence manager settles in to address the mountain of paperwork on her desk. The usual reports, documentation, reviews and scheduling sit in front of her. With few quiet opportunities like this, she is eager to be as productive as possible.

Within the hour, the stillness is broken by the ringing of the telephone. "You have got to come out here right away and see your consumer - you won't believe what s/he's doing!!" says the shrill voice on the other end of the line...

How many of us have been on the receiving end of phone call like that? Whether from an employer, day program or other agency, the police or other authorities, teacher, or fellow staff person, that familiar feeling of "oh no, here we go again!" is one many in the field of sexuality and developmental disability have experienced. Calls such as this can instill a variety of feelings - fear, disbelief, confusion, anger. Sometimes we must summon the strength to have patience with the consumer (or caregiver) in addressing the situation, perhaps for the tenth or one hundredth time. Other times we must summon the courage to suggest new solutions, or to address a systematic or organizational cause that may actually

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elicit the challenging behavior we are called to stop. Once in awhile, we must even summon the will to keep from laughing out loud at a situation that is comical or absurd.

Many feelings, questions, and fears often swirl in the background as an agency, school, or parent considers providing sexuality education for people who have developmental disabilities. Some of these are vestiges of the myths and misconceptions regarding sexuality in general that still abound in our society. Others are related to societal myths and misconceptions about people who have developmental disabilities. When the two subjects merge, the result can evoke many responses (for a complete history, see Appendix).

One method that can be used to address the questions, feelings, and fears that can arise from these discussions is to actively name and acknowledge them at the outset. By naming these questions, feelings, and fears, we can then move on to the work ahead. Overhead 1 (page 54) provides visual assistance in starting this discussion.

Several outcomes can result from participating in this exercise. Participants can feel validation when they realize that others in the group have similar (or even more challenging) questions and issues on this topic. Some types of questions and feelings can give the trainer insight into the issues which are most important to the group. Thus, the trainer can structure the training to concentrate on these areas. Responses that indicate misinformation or myth can provide an opportunity for these to be corrected with accurate information. The activity also provides a chance for networking - as individual similarities, strengths, and experiences are discovered through the brainstorm, the group can begin to share with each other their areas of expertise and success stories.

Activities 2 and 3 (pages 60 and 62) provide participants with a chance to assess their own values and sense of comfort with some of the issues that can arise when dealing with sexuality and people who have developmental disabilities. Again, this exercise can assist participants in evaluating their own ideas and beliefs about the subject. All people need not be totally comfortable and knowledgeable about all areas of sexuality in order to facilitate an effective program for consumers or students. It is important for each person to be aware of their own comfort level (and not merely their knowledge level) as tasks are assigned. Areas where one's personal values and philosophy may differ significantly from agency mission or

state policy are also important to explore. In such cases, clear statements of what is expected from each employee with regard to developing and implementing a sexuality training program can avoid misunderstandings or problems later on.

To address myths and facts, Activity 4 (page 64) gives participants an opportunity to explore and debunk ideas present in popular culture. This activity can also provide insight to the individual and the trainer about which areas participants are educated about, and which areas could use further education and attention.

A word about the goals of the program you wish to implement...

It is as important to talk about and define the goals of your program as it is to explore individual feelings about the idea in general. Take a few moments to brainstorm what participants would like to learn, and what information they are most in need. How do these compare with your agency's goals in providing it? There are many reasons an agency may embark on the process of providing sexuality education:

- to fulfill the agency mission statement,
- in response to "problems" or incidents that seem to be sexual in nature,
- in response to requests from consumers themselves,
- to address liability issues,
- because your supervisor said so,
- to provide a pro-active framework that supports consumers in exploring their own unique sexuality,
- to prevent exploitation or abuse, or
- to comply with local, state, or federal law.

Investigating and understanding the motivations for your own program's journey into sexuality education can lend vital insight into how you may help in this effort. It may also dictate how comprehensive the sexuality program is, who must authorize it, and what

benchmarks will be used for evaluation. Some of the factors listed may indicate that a variety of different approaches are needed. Depending on the situation, some motivations to provide sexuality education may actually be at odds with the needs of the consumer or caregiver. For example, an agency light mistakenly assume that "proper" sexuality education would eliminate sexual feelings in the consumer. Careful examination of the motives and desired outcomes for providing sexuality education is an important first step, BEFORE beginning any program. If you are an outside educator or agency commissioned to provide sexuality education, it is important that you have a grasp of the above issues for every agency with which you work.

Not all situations that appear to involve sexual issues are best addressed by sexuality education. For example, some behaviors (sexual philias, some crimes of a sexual nature, sexual dysfunction) are better served by other interventions that are specifically designed to address them. Instances in which a sexuality educator is called in to address situations that in reality require an entirely different approach are all too common. Sexuality education is not an "all purpose fix" nor is it a substitute for counseling or therapy. Sexuality education does not take the place of qualified medical advice from a licensed clinician. Nor is sexuality education sex therapy. It is important to carefully determine the reasoning behind providing sexuality education to ascertain that it is within your scope of knowledge, qualifications and capability, and ask for assistance or support if needed.

In addition to the rationale your organization has for providing sexuality education, it is equally important that the sexuality education itself be guided by a goal or rational. One philosophy that will result in the optimum learning environment for such an effort is that all sexuality education that occurs will be:

✔ **Accurate,**

✔ **Age-appropriate,** ***and***

✔ **In ways that are useful**

What does this mean?

Accurate: Providing accurate, factual information must be the foundation of any sexuality education effort. This includes adequate preparation by the presenter, so they are knowledgeable in the areas about which they will speak. A skilled presenter is also willing to say "I don't know" when necessary. Admitting that a question or comment is out of one's area of expertise, then finding out where to get an answer, is a valuable skill. This process also models to the participants the manner in which one might seek out answers themselves to questions that arise in the future. By sharing where one might find information, like a reference book, library, school nurse, physician or counselor, the facilitator can illustrate this important skill.

Age-appropriate: This is a term that takes on particular importance when working with communities of people who have developmental disabilities. Because of the long-standing practice of labeling people with terms or developmental age (rather than chronological age, i.e. "he functions at an eight-year-old level"), determining exactly what age-appropriate refers to is highly significant. Consider the following:

- Malik, 13 years old, is labeled "low functioning." He has recently sprouted some facial hair, and his voice is beginning to change. What sort of age-appropriate information should he receive?

- Terry, 49 years old, has an IQ of 24 and attends a day habilitation program for people who have not succeeded at the sheltered workshop. What are important sexuality issues for Terry at this point?

- Leroy, 40, acquired hepatitis as a teen while in the state institution and his current status is that he is an asymptomatic carrier of this disease. His relationship with John (also a person with developmental disabilities), appears to be progressing toward sexual intimacy. What sort of information could be provided to Leroy about expressing his sexuality in a healthy manner?

- Years ago, doctors told Emily's parents that "she will always be 6 years old" in describing her ability and potential. Now a grown woman, she has expressed an interest in birth control pills. Her parents are in shock - this is not normal for a 6 year old! How could this situation be approached?

- Shanda attends an early intervention pre-school program. The standard curriculum for pre-schoolers includes information on taking care one's body, safety rules, and "stranger danger". How does this affect Shanda?

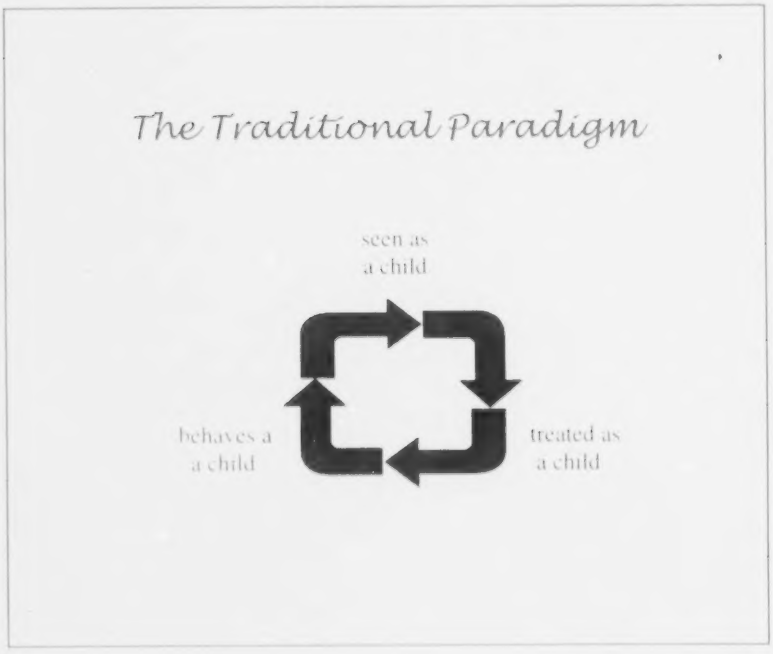
In each of these situations, how does one determine what constitutes age-appropriate information? Because the changes, opportunities, and challenges of our sexual selves are tied to chronological age, it is this age that must be used in planning a program that adequately meets the needs of the individual or group.

For example, a group of youth approaching 11 or 12 years old are already or are about to begin experiencing puberty. Therefore, age-appropriate information for them includes puberty education. Whether these youth are labeled as disabled or not, puberty information is essential at this point. The methods by which one presents the information may differ, and the time used to cover such material may differ, but the actual content of the material must be the same. In order to be prepared for the coming changes, all youth require this information.

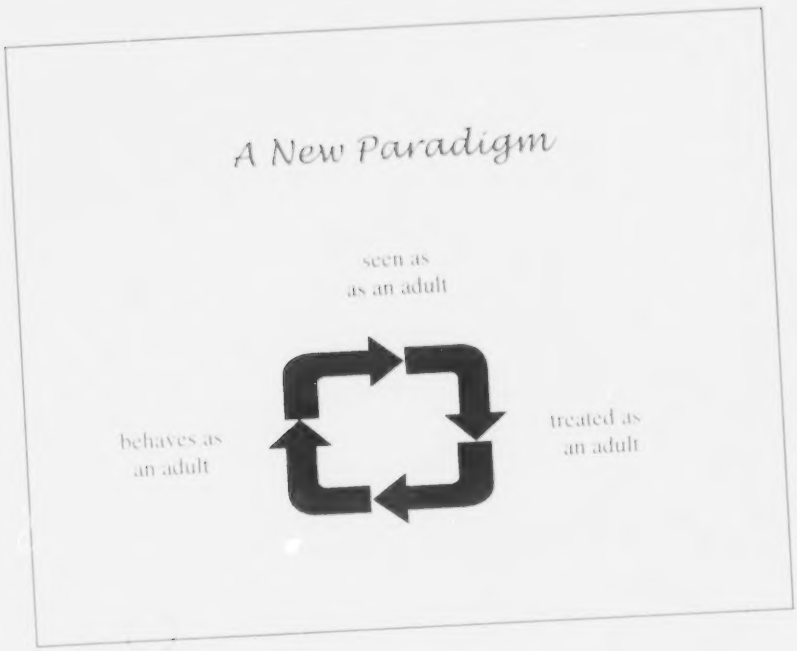
As another example, all children go through the process of learning how to make determinations about social situations - how to greet family, friends, and acquaintances, how to deal with strangers, who and how to ask for help. In everyday society, these are important skills to master, yet the actual process of learning these skills is often taken for granted. After a certain period of time, children are expected to successfully know a variety of social cues like: who to kiss, hug, or shake hands with, how to cross the street without holding onto an adult's hand, and so forth. Yet there are many adults with developmental disabilities who have not been expected to master these skills, or not been provided with the training needed

to do so. Although these are clearly social skills that aid in one's successful passage through society, societal mythology dictates that these individuals are "cute" when they exhibit such age-inappropriate behaviors, or that they are unable to learn such behaviors and therefore serve as objects of sympathy or pity. Age appropriate in these cases means supplying the education and practice to an individual that is required to demonstrate expected social interactions just as other people of similar age do.

Because people who have developmental disabilities have traditionally been viewed by society as child-like, a cycle of self-fulfilling prophecy is perpetuated:



But, by gauging age appropriate learning and skills development an individual can achieve their full potential, as illustrated by the following diagram:



For individuals to truly become integrated as full members of society, they need to be viewed as such by others.

In Ways that are Useful: This idea incorporates several elements. As alluded to above, it encompasses the idea of providing learning experiences from which the individual can learn best. For instance, the standard anatomy and physiology charts that show reproductive organs without any context are difficult to decipher at best. These types of charts have been used for many years as tools in sex education but they may not provide information that is useful or useable for some audiences. When teaching about social skills, it means not merely talking about such skills, but actually providing practice for real-life situations.

Another element of this idea has to do with what the person or group really wants to know about. The curriculum may call for a brief primer on AIDS education, but the group may really have "yeah, but how do I get a date?" on their minds. In this case, relevance to the real issues of the audience is what is "useful". This does not mean that any curriculum or training should be scrapped if a person indicates they are interested in other topics. It does

illustrate that being in touch with one's audience is important. It can provide vital clues to what concepts are real for them in the here and now, and how important information on your agenda can be incorporated into their real-life experiences and concerns.

Usefulness also means "how does this affect me now?" If the lesson is condoms, where does one get them? Am I allowed to have them? How much do they cost? When do I use one? How do I put one on? Always remember that:

⇒ practical knowledge is ⇐

USEFUL

and

USEABLE

knowledge

Chapter Two

Why Do I Do This?

Effects of sexuality education for people who have developmental disabilities...

Thirteen year old Justin is in the school hallway walking to lunch. Suddenly he spots her - the girl he is sure he is in love with, although they have never met. He often sees her as he makes his way to class, puts his things in his locker, or waits for the school bus. Although he is a special education student and she is not, he just knows this can work. He knows she will be his girlfriend, if only she knew of his feelings for her. Today is the day he will let her know. He strides toward her as she is taking her lunch out of her locker, and kisses her on the cheek. He tries to tell her his name, and about all of the feelings he has for her, but she does not hear him. She is screaming, and backing away. A couple of teachers head down the hall toward them, to find the source of the commotion.

Later that day, the police come to get Justin out of class. The girl has charged him with sexual harassment, and he must face school and judicial penalties for such behavior. Although Justin tries to explain his motivation in approaching the girl, no one seems to understand what he is saying. And, he doesn't really understand what they are explaining to him, either. All he knows is that the girl is still very upset. Meanwhile, school administrators, the police, and the students' parents try to make sense of a policy that doesn't quite seem to address the real issues behind this incident...

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There are many outcomes and benefits that sexuality education can have for people who have developmental disabilities :

Why Do I Do This?

The Effects:

→ Empowerment

→ Skill building

→ Learning new information

→ Communication

→ Setting the stage

→ Articulating goals

→ Preventing negative outcomes

Sexuality is one way people who have developmental disabilities are just like everyone else. The changes and choices of growing up impact all human beings. Regardless of ability status, young people between 9 and 16 years old experience puberty. In a world in where their difference from others is constantly stressed, puberty is a great leveler, one thing that happens to everyone. As one youth in a training once asked incredulously, "So even people in Russia get periods?" Indeed, in a world of difference it is one thing that we all have in common. The realization of this fact can be very empowering for people who are constantly viewed as different. A sense of empowerment can provide critical boosts in self esteem and self-confidence.

Effective sexuality education provides a framework from which people can learn to communicate without embarrassment or guilt. By providing a vocabulary of anatomically correct words (rather than "pet," slang, or family names for reproductive organs or processes), we can contribute to the successful integration into the adult level of interaction, as illustrated by the new paradigm on page 16. An added benefit of knowing correct language for body parts and processes is that if a person has a health concern or question, they can describe their feelings or symptoms more clearly to their caregiver, school nurse, or

clinician.

Because sexuality is a basic condition of being human, providing sexuality education can assist individuals who have developmental disabilities in expressing their sexuality in ways that fit their needs and abilities. The rewards and responsibilities inherent in expressing one's sexual self form the perfect backdrop for discussions of appropriate behavior. This can include discussions of social behavior and sexual behavior. The network of complex social interactions can be difficult to navigate. Sexuality education can provide information and an opportunity to practice skills that assist in learning to recognize and respond to social and sexual situations.

Discussions of the responsibilities and milestones of sexual behavior (parenting, becoming life-long or marriage partners, ensuring sexual health, etc.) can also assist individuals in envisioning their future. Without such discussions, the individual (or those around him/her) may underestimate what he/she is capable of achieving; likewise it can also form the basis for concrete plans to move the individual toward realistic goals that best match their abilities.

For example, many people who have developmental disabilities aspire to marriage - and 92% of all marriages among couples who both have developmental disabilities last (versus 40% of traditional marriages). There are several rationales postulated for this staying power. Such couples appear better able to put aside sex role stereotypes in order to get the work of running a household done (weaknesses in one area in one individual are made up for by the other in the couple, regardless of the type of task). Also, most couple who eventually marry have had to jump through so many hoops to get there (often spending years convincing caregivers, the state, family, etc. that they are prepared), that they have had ample time to explore their feelings and commitment to each other.

Sexuality education can provide information and skills to recognize and prevent sexual abuse or exploitation. It can also assist in providing the framework to understanding and avoiding behaviors that are illegal or socially inappropriate.

The feelings, facts, biology, and relationships taught about in sexuality education are experienced by all people -- regardless of ability status -- and provide vital opportunities for

people who have developmental disabilities to feel "like everyone else".

Chapter Three

Who Is My Audience?

Definitions of developmental disabilities

As I rounded the corner from the living room of the group home to the adjoining dining room, I noticed that MaryAnn was not at the table eating dinner with the rest of the residents. Instead, she was on the living room couch, masturbating. Sensing that there must be some explanation for this inappropriate behavior, I asked in as nonchalant a tone as I could manage, "What are you doing, MaryAnn?" MaryAnn stopped what she was doing to address the ignorance of my question, the answer to which was so obvious to her. She replied in a patient manner, "I'm all alone in here. I'm masturbating, and that's a private thing." She continued, "Privacy is when you're all by yourself, that's what they taught us. Well, here I am, all by myself," (she gestured to the empty room for emp[illegible]s). Meanwhile, those at the dinner table had a full view of this entire scene...

There are several definitions of developmental disability. Exploring them will provide insight into what the term actually means. Doing so can also lend helpful information for those about to craft or deliver a sexuality education program.

Definition #1: Individuals with Disabilities Education Act (IDEA) of 1990

- Significant Sub-Average IQ (two or more standard deviations below mean; <70)
- Deficits in Adaptive Learning

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♦ Manifested During the Developmental Period

[Public Law 101-476, Federal Register, 57 (189), Sept. 29, 1992, p. 44801]

This definition focuses on three ideas: IQ, learning deficits, and the time period in the individual's life that the previous two conditions appear.

Definition #2: American Association on Mental Retardation

♦ Significantly Sub-Average Intellectual Functioning

♦ Limitations in two or more adaptive skills areas:

Communication	Self-direction
Self-care	Health & Safety
Home living	Functional Academics
Social skills	Leisure
Community use	Work

♦ Manifests before age 18

[AAMR, 1992, available at <http://www.aamr.org/FAQMentalRetardation.html>]

This definition, although more descriptive and comprehensive, is still rather similar to the first. The ideas of sub-average intellectual functioning and deficits in adaptive behavior, as well as time of onset, appear again, just as in Definition #1.

To put these definitions into perspective, let's take a look at their components.

What is IQ? IQ, or intelligence quotient, is an idea that Alfred Binet attempted to describe and quantify in the early 20th century. From Binet's work to the present, IQ has come to be operationally defined through one's skill at a series of mental tasks and exercises. Many tests and scales attempt to measure this ability, using a variety of methods. Yet, at the foundation of all of these measures is a basic idea.

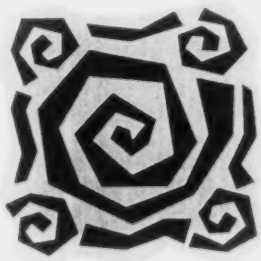
Simply put, IQ is the ability to think in abstract concepts. Why is this important? Because the world is often a very abstract place. Although a continuum exists, many of the

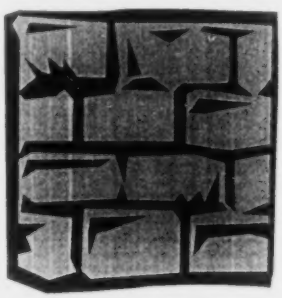
social tasks demanded in everyday life require a high level of abstract thinking.

CONCRETE ——————————————— ABSTRACT

Abstract situations depend on interpretation. Each person interprets questions and information uniquely, based on their own experiences. In the anecdote that begins this section, MaryAnn takes some pieces of information (masturbation is done in private, privacy is when you are all by yourself) and very literally interprets them. She is, in a concrete sense, displaying exactly what she has been taught.

In the areas of social skills and sexuality, our job is to take some very abstract concepts and make them very concrete.





Everyone operates at some level on this continuum. Some very brilliant thinkers have come to their discoveries and inventions through very concrete methods. Concrete thinking does not mean that a person is somehow less "smart" than others. People merely function at varying levels of abstraction. Many things can impact the level of abstraction one reasons with - for example, concrete thinking is common when one is learning a new task or concept. If a person has had no other similar experiences to compare or relate this new task to, they begin to understand it on a more concrete level at the outset.

Another interesting irony in the area of concrete versus abstract reasoning skills is that current teaching methods for people with developmental disabilities may actually develop concrete skills at the expense of developing those at different levels of abstraction. Since it is a common teaching strategy to break activities up into simple tasks and reward

them (rather than present them as whole ideas), this may actually be unintentionally strengthening and perpetuating concrete reasoning in those who are taught in such a manner.

Adaptive learning, another component of these definitions, will be explored in chapter five.

The developmental period, also mentioned in both definitions, refers to the period of infancy, childhood, and adolescence. Exact age limits vary from state to state, but all fall within the range of ages 0-22 years of age.

Definition # 3 - An alternate definition

♦ Developmental disability refers to a level of functioning which requires from society significantly above average training procedures and superior assets in adaptive behavior, manifested throughout life.

♦ The person with developmental disabilities is characterized by the level of power needed in the training process required for him/her to learn, and not by limitations in what s/he can learn.

♦ The height of a developmentally disabled person's level of functioning is determined by the availability of training technology and resources society is willing to allocate and not by significant limitations in biological potential.
[Marc Gold, Community Based Residential Services Staff Training Manual, Division of Developmental Disabilities, New Jersey, 1990]

This definition represents a significant departure in ideology and underlying assumptions from the previous two. Concepts of IQ, limitations, and adaptive learning are noticeably absent. This conceptualization of developmental disability focuses not on the individual, but on the environment and resources available to address each person's particular learning style and needs. Definition #3 is restated below to emphasize words that

demonstrate how this definition dramatically shifts focus and responsibility:

♦ Developmental disability refers to a level of functioning which requires from society *significantly above average training procedures and superior assets in adaptive behavior*, manifested throughout life.

♦ The person with developmental disabilities is characterized by the *level of power needed in the training process* required for him/her to learn, and not by limitations in what s/he can learn.

♦ The height of a developmentally disabled person's level of functioning is determined by the *availability of training technology and resources* society *is willing to allocate* and not by significant limitations in biological potential.

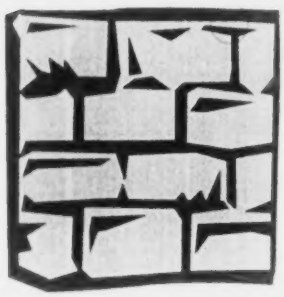
This definition puts the responsibility onto society for finding and providing adequate teaching techniques and materials. Assumptions underlying this definition include:

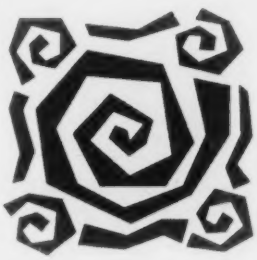
⇒ Developmental disability is not a general phenomenon.
⇒ Intelligence, as defined by tests, is a concept of little use.
⇒ No behavior clearly defines potential.
⇒ Prediction describes context.
⇒ Adaptive behavior can be assumed.
⇒ Development is lifelong.
⇒ Train, do not test.
⇒ Developmental disability is most meaningfully conceptualized as a phenomenon existing within the society which can only be observed through the depressed performance of some of the individuals in that society.

According to this definition, it's up to us to find the learning channels and techniques that each individual person with developmental disabilities can best learn from. Disabilities

are defined by the lack of adequate societal support (economic, educational, etc.). Given adequate technology and resources, the individual has potential equal to the potential of all other members society. The resources and support necessary to create optimum learning conditions for each individual do not currently exist in American society. Educators must strive to find creative solutions to address each individual's unique learning style and needs.

These three definitions all clearly demonstrate the task ahead of us in providing sexuality education. By utilizing the resources that are available (or possibly by creating new ones!), we need to integrate the concrete world of the individual with a developmental disability with the abstract information needed to make informed decisions.





Another continuum that can also provide insight into teaching strategies for people who have developmental disabilities is that of sequential versus random thought processing.

sequential ——————————————— *random*

Sequential processing refers to working or thinking one by one, in order, through a series of tasks or ideas. Random processing requires the ability to manipulate several tasks or ideas at once, juggling them successfully.

The person who pulls into the driveway but cannot get out of their car before the song on the radio has finished playing is an amusing example of sequential processing. In a similar manner, a sign posted on the door of a restroom stall that said "Employees must

wash hands before leaving" prevented a consumer I once worked with from leaving that stall. Her manager explained many times that the intent of the sign was to remind people to do so before leaving the room in general, not the stall (since the stalls themselves had no sinks). However, it made no sense to her until the sign was repositioned to the exit door of the restroom. Her sequential style of encountering and reacting to stimuli one by one and in the order presented, served to prevent her from seeing the "big picture" of understanding the intent of the sign rather than placing undue significance on where it was displayed.

As with the concrete versus abstract continuum, all people, regardless of ability status, fall somewhere on this scale. Higher proportions of people who have developmental disabilities tend to fall toward the sequential side of this continuum. As with the concrete-to-abstract continuum, this bias may be unintentionally strengthened by the modes of teaching used with people who have developmental disabilities. Often times, the teaching modes used go to the extreme of breaking all information into sequential patterns, rather than encouraging some use of random processing. With the concrete-to-abstract continuum in mind, strategies for sexuality education will need to take into account a predominantly concrete learning style influenced more by each separate step or action, while remaining open to approaches that teach a complex set of whole ideas. Effective sexuality education will incorporate both "big picture" and concrete lessons when appropriate.

Chapter Four

What might slow me down?

Barriers to effective teaching

Alex approached his mom and asked, "Mom, where could I buy some handcuffs?" Although initially shocked and surprised at this unusual question, Alex's mom decided to gather a little more information to get a better picture of what he was asking, and why. "Tell me about your interest in handcuffs, Alex?" "Well, for sex," said Alex, as if it should have been readily apparent to his mom. Even more surprised by this answer, she pressed on nevertheless, "Tell me more." "Well, in a magazine that got passed around the bus - a dirty magazine - all the pictures in it have people with handcuffs and stuff like that. I want a girlfriend, but I don't have handcuffs or any of that stuff. I guess I have to get some before I get a girlfriend - so where can I find handcuffs, Mom?" .

This situation illustrates the concrete versus abstract concept explored in the previous chapter. In Alex's concrete reasoning, one must need all the "props" that characters in explicit magazines had, in order to get a date. The magazines are about sex, the people in the photos have all manner of accouterments, therefore, there must be things one needs to acquire in order to be a sexual person. This vignette about Alex and his Mom also illustrates one of the major barriers to effective teaching: it can be difficult to find resources that use clear, concrete illustrations (without objects the typical home or similar setting does not have). Although the anecdote is humorous, it also demonstrates the need to carefully screen diagrams and photos used in sex education efforts for any unnecessary or distracting items.

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For example, a colleague shared with me a series of drawings that had been developed to teach about social interactions and sexual behaviors with people who have developmental disabilities. The drawings included scenes of people spending time together, families engaged in a variety of activities, and individuals taking care of personal hygiene and other tasks. During the development of this set of drawings, a focus group of people with developmental disabilities was used to determine whether each drawing clearly elicited the concept or point the curriculum and artist had intended.

One drawing portrayed a young man masturbating in his bedroom. The point of the drawing appeared clear. However, upon presenting it to the test group, the consumers exclaimed, "Look at those flowered curtains! I would love to have curtains like that in my room. Do you think they have them at K-Mart? How much do you think they would cost?..." Not one person even noticed the young man in the picture! This drawing was redone by the artist, who substituted a plain striped design for the curtains. The intended subject of the drawing became immediately clear to the focus group when presented with this new version of the drawing.

One obvious thing that can slow us down is the lack of suitable materials. Pictures make great learning tools, but where can we find clear pictures representing what we want to talk about? Locating appropriate diagrams and pictures for a sexuality education program can be challenging. Consult the Resources section for organizations and companies that produce these materials.

There can be other barriers that may slow down your efforts. Consider some of the many channels people use for learning:

- sight
- hearing
- touch, manipulating
- writing
- doing, experiencing

Figuring out how best to use the available learning channels (sight, hearing, writing, doing, etc.) for your audience can be a temporary obstacle. We all have a "favorite" learning channel - some people take notes, others listen, still others observe and do. People who have developmental disabilities are no different. However, if an individual's disability serves to block any of the learning channels, then you need to creatively figure out a way around that obstacle. You must find the most effective way -- *the way in which the individual understands best* -- and apply the appropriate teaching method. In order to provide quality sexuality education, one must find the most effective learning channels for each individual. Many times this means that structuring a learning experience for a group requires the educator to provide several different ways for the participants to connect with the information being presented. Our job is to find ways to help access materials in a concrete way that utilizes the learning channels that are available.

Aside from recognizing the important role of learning channels, there are other conditions that may hinder learning:

- attention span
- sensing abilities (sight, hearing, etc.)
- decreased motor function
- medication

There are also other factors to consider when preparing a sexuality education program for people who have developmental disabilities:

✔ Past Learning:

- What are the experiences of the individuals?
- Have they lived in a single-sex institution?
- With their families?
- In a community residence?
- On their own?

How can these experiences affect their present knowledge, potential questions, and behaviors?

✔ The Present:

- In what sorts of relationships are the individuals involved?
- Have any been partnered or married?
- Are any parents?
- Are there any significant influences or rules regarding socialization or sexual behavior in their living environment?
- Have any participated in a sexuality education program before?
- What are the attitudes toward sexuality education of the parents/guardians/families of the individuals who will participate in the program?

✔ The Future:

- What are the future goals of the individuals?
- What are the goals of their individual habilitation plans?
- How well do these sets of goals match or complement each other?

✔ Society:

- Attitudes - personal and societal.
- The Law - are people with developmental disabilities treated differently under the law? How? Why?
- Informed consent to sexual activity or medical treatment.

More information about past, present, future and society...

Past:

What has been the individual's educational experience to date? Whether mainstreamed, in a separate class or school, home schooled, or some combination of those experiences, they already have a body of knowledge about basic social interactions. What has been their experience regarding their living situation? Their experiences with social interactions? Opportunities for learning about sexuality? Some settings may have prepared the individual more effectively than others, so you must first assess what they already know. There are some professional tools available that address assessing the social/sexuality knowledge of people with developmental disabilities. Consult the Resource section for information.

Present:

Your audience's present circumstances - friends, social activities, interests - also play a part. Keep in mind that some lessons or "facts" the individual has gleaned may be misinformation. Misinterpretation of available information can also play a role in what the individual currently knows about sexuality.

Sometimes, agency policy or institutional practice can contribute to the unintentional learning process. In one situation I was called in to consult on, I was asked to address a group of consumers regarding appropriate/inappropriate places to have sex. Several consumers at the community residence (a single-sex group home for women) were engaging in sexual behaviors in inappropriate places (the basement of the residence and the broom closet at work). When I arrived, several of the staff met me at the door, obviously concerned. I assured them I would find out what I could about the situation. As I sat down, one of the consumers said "Well, I guess you're here about the house rules, right?" Before I could respond, she continued, "We understand the house rules here; we're doing our best to follow them." She motioned for me to follow her to the bulletin board, where the "House Rules" were posted. *Rule # 1 - Residents have the right to socialize with whomever they choose, including the right to have sexual relationships as they choose.* "OK, so does anyone have any questions about this rule?" I asked. "Keep reading," she replied. *Rule # 2 - No men allowed on the 2nd floor.* "What's on the second floor?" I asked, already having an idea of what the answer would be. "Our bedrooms!" the group replied in unison. "We know all about public and private, appropriate and inappropriate. We learned all that a long time ago. But, we didn't want to break the rules either, so...what are we supposed to do?" After further discussion about the house rules with the group, and later a lengthy chat with the agency administrators, it was decided that Rule #2 must go. Originally intended to protect the consumers from sexual exploitation (and most likely to prevent consensual sexual activity as well), the rule actually served to encourage the consumers to be covert and creative with regard to expressing their sexual feelings. Although a humorous anecdote, the story of "Rule #2" demonstrates ways in which agency policy can contradict itself, or lead to confusion and behaviors that the original policy sought to suppress.

Future:

A consumer's future (including their goals and individual habilitation plan) must also be taken into consideration. Those goals are paramount in formulating an appropriate habilitation/training plan. Merely ignoring the consumer's own goals (or wishing them away) will not prevent the consumer from exploring their own sexuality. It will prevent that person from having access to important knowledge and skill building opportunities that may assist them in expressing their sexuality in a safe and appropriate manner. Ignoring the consumer's needs may also unintentionally teach the consumer that they are not an active and important participant in their own destiny.

Is there anything in the individual's past, present, or future that may help or hinder your efforts?

Society:

Societal attitudes toward disability and sexuality can be a source of comfort or conflict. Legal issues can also present themselves, especially regarding informed consent. Consult the Resources section for works that address this in detail.

With all these considerations in mind, try not to lose sight of your goal - your job is to find ways to help access materials in a concrete way that uses all the learning channels that are available.

Chapter Five

How Do We Learn What We Know?

Adaptive learning

The group listened attentively as the presenter reviewed proper condom use. To demonstrate, he opened up a condom and rolled in onto his hand. He showed how sturdy and strong the condom was. From the questions and responses of the group it was clear that most of the group was following along. One young man in the middle of the room looked confused. The presenter reviewed the information several more times, then moved on to another topic. About fifteen minutes later, the confused man suddenly jumped up out of his chair with an "ah-ha!" expression of his face...finally he understood! He threw his hands in the air and declared, "now I get it -- if I want to have sex, I just put condoms on my hands!"

Now that we've covered the goals, effects, and potential challenges in this process, let's take a look at learning and the unique job of making some highly complex ideas easier to understand.

There are several different definitions of "developmental disabilities". Each include the idea that a person who has a developmental disability has less success with abstract concepts and adaptive abilities. What are these? Abstract concepts are ideas, like "relationship", "society", "love". You can't really see them, although you may see things that tell you they are there.

Some abstract ideas are really quite simple, like when someone asks "How are you?" What is an appropriate response to that question? Usually "Fine, thank you," or "Good,

how are you?". When someone asks you that question, they're really asking you to participate in a very abstract social interaction. To someone who functions on a more concrete level, the response to this customary greeting may be lengthy, involved or socially inappropriate. A simple "how are you?" might elicit a concrete response like, "...well, when I woke up this morning I felt a little sick to my stomach, then I had some toast. Toast is my favorite breakfast food. Then I had to hurry up and get to the bus stop. My stomach felt better when I got there but then I got a little headache, but I love my job, I was so I happy to be going back to work after the weekend..." It is important to note that the concrete answer is not at all wrong, rather, it is entirely (painstakingly) accurate. However, the detail and length of the response does not follow customary social patterns.

The world can be a very abstract place. Our job, then, is to take some abstract ideas and make them as concrete as possible. For example, most people have an idea of what the abstract ideas of "privacy" or "love" or "caring" mean to us, but how do we explain them in a concrete way?

The notion of adaptive abilities came up in two of the definitions of developmental disability in Chapter Three. Adaptive abilities are simply the success with which a person encounters a situation and acts appropriately. We all do this, usually unconsciously, by taking important clues from the situation and comparing them (in our memory) to other similar situations in order to make a decision about what to do next. When you go shopping at a new grocery store, for instance, how do you know how to act? You probably think back to other stores you've been to, and formulate some ideas about what would go on and how you would respond. You may even correctly guess where the produce, dairy, and checkout areas are, even if you have never been to this store before. That's adaptive learning: The ability to select cues from a new environment or situation and cross-reference them with other situations we have experienced in the past, and use that information to act appropriately in the new situation. People who have developmental disabilities have a more difficult time doing this, so this gives us important information about what might be successful or unsuccessful as we set out to provide learning opportunities in sexuality education. People who have developmental disabilities can often times remember a number

of details about their experiences. The difficulty arises when sorting out the significance of all the details they remember. A person with a developmental disability will remember the same amount of information as others. However, the type of details they recall are not always relevant to the task at hand. For instance, they may judge that the color of a latex condom is far more vital to remember than how to pinch the tip and properly roll it on a penis.

There are some social situations in which we have to put together adaptive abilities, abstract ideas, and novel situations. A friendly wave might be your usual greeting to your neighbor, but if she has just survived a plane crash, a hug and more lengthy chat might be more appropriate. One never kisses strangers, but in the receiving line at a wedding, you may find yourself doing just that with a string of distant relatives and acquaintances. The subtle nuances of social interactions are complex and constantly changing. Although we aren't frequently consciously aware of it, we constantly make social judgments about the variations in our interactions with others.

When you are working with people who are challenged by the process of sorting out the wide array of possibilities in social and sexual situations, success will come from frequent practice and review.

Chapter Six

Why is S/He Doing That?

Making an abstract world more concrete

We were in the common social room, a comfortable setting in the apartment complex where Brian and his peers lived. Brian volunteered to explain to the group gathered about the importance of safer sex in the age of AIDS. Everyone listened attentively, including the sex educator presenting this 12 week series on sexuality. "Well, because there's AIDS, and a lot of other germs you can pass around through sex, it's important to know how to protect yourself and your special girlfriend," he began. "Liz is my special girlfriend, and I love her very, very much." He reached for her hand, and they exchanged loving glances before he continued. Brain and Liz were the pride of the supported living staff; they obviously cared deeply for each other and enjoyed each others' company. They had also mastered relationship building. They had worked out the mechanics of daily life, each helping the other with tasks that were challenging or disliked. One staff person had remarked that he knew quite a few non-disabled couples who found it difficult to strike such a workable and equitable balance. "We hope to get married some day, right now we're fiancees. We do things together, like cooking dinner, going to the park, watching TV. We help each other – I help her with figuring out what everything will cost when she makes a shopping list, and she helps me to figure out what bus to take to the mall, and reminds me to keep my apartment not so messy. That's what special people do for each other – they care about each other. I love her so much. Because we love each other and care about each other so much, we want to protect each other. We always use a condom when we have sex – that's what you do with

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people who are special to you. She's my special girlfriend, and I'm her special boyfriend. So we make sure we always have some condoms, and her and me both learned how to use them." Brian asked for a condom from my teaching kit of birth control methods. He then opened it up and narrated the proper use, demonstrating how they unroll, how strong they are, and highlighting proper disposal techniques to avoid spilling any semen. He even included how to get them, and shared that a staff member always had some in her desk drawer for any residents that wanted them - even if they just wanted to see what one looked like or practice with one by themselves.

His overview was perfect; I was mentally patting myself on the back for my role in the obvious accomplishments of this prize pupil. The careful explaining and repetition I had engaged the group in had really paid off for this young man, and it showed. Sensing the importance of educating consumers about real-life issues long before it was the norm, the agency sponsoring this independent living program had taken a pro-active stance, supplying the currently available literature and posters on HIV prevention. They had sponsored this educational series, not because it was required (it wasn't, at that time, by the state body overseeing residential settings for developmentally disabled individuals), but because it was important. It was apparent that Brian had not merely memorized my own spiel on the condom, but had thought over each step in condom use and fit it to his own situation. He had put it in a format that he could use. His comprehension of this method, it's use, where to obtain it, even its advantages and disadvantages for the developmentally disabled couple, was flawless. I patiently waited for him to wrap up his comments. I had already begun formulating the wonderful praise I would lavish upon him. Perhaps he could become a peer educator in his supported living program! Perhaps he could go on the safer sex lecture circuit as a speaker on developmental disabilities and HIV education! Perhaps I would get a raise!

I focused back again on his concluding comments "...so like I said, it's just what special people do...Now, when I have sex with Barbara from work, or some other girl who is not my

special girlfriend..." OH NOOOOOOOOO!!!!!! My heart sank. Liz slumped in her seat, her eyes portraying obvious pain and disbelief at what she was hearing. Brian continued "Well, then I don't use condoms because they're not my special girlfriend. You should always use a condom with your special girlfriend, because that's what you do with people you care about. With all the other girls I have sex with, I don't use a condom. Because I'm pretty smart – I understand about all this AIDS stuff. That's what they say to do," he gestured at an AIDS awareness poster hanging in the room. It portrayed a couple in an embrace, and the text read "Because you care about each other - use a condom". "I understand what they're saying. And I do it." Liz was now turning red with anger, her fists shaking. Brian was blissfully unaware of the disclosure he had just made to his "special" girlfriend, and indeed to the entire room. My own thought process had gone through an amazingly swift 180 degree turn. What was he saying? First, he was sharing that he had many sexual partners (much to Liz's apparent surprise). And, he was demonstrating that he HAD understood the HIV prevention messages surrounding him completely!

In a clear example of concrete reasoning, Brian understood from that poster (and from many of the early HIV-prevention messages aimed at the public during this time) that "special people use condoms." And then he reasoned further – "when you have sex with someone you don't care about, however, no need to bother". Although the slogan on the poster appears at first glance to be clear and unmistakable, it does assume a basic level of abstract reasoning to fully grasp the desired message. Brian, operating at a different level of abstraction, understood the message in a different way (certainly not in the way it was intended) and therefore had internalized information that could be ultimately much more harmful than helpful. Paying attention to certain parts of the message ("because you care about each other", equal in his mind only to his concept of and feelings toward his special girlfriend) he had picked up the "wrong" cues, assigning more importance to some aspects of the message than others. By not fully interpreting the appropriate cues ("use a condom", and the inferred "Every time!"), he had participated in harmful behaviors he thought were protecting him from HIV exposure.

Sometimes the ideas or behavior of a person who has developmental disabilities may seem unexpected or unusual until we stop to consider them in terms of abstract learning and adaptive abilities. (Remember the vignette that opens the very first section, as someone screams into the phone "*You have got to come out here right away and see your consumer - you won't believe what s/he's doing!!*") Sometimes the explanation - and clues toward how to address the situation - lies in viewing it from a more concrete viewpoint. A look at the environment, or how the behavior has been addressed in the past may yield information on what's really going on.

If a person who has a developmental disability walks up and hugs even complete strangers, for example, is it because they are hopelessly confused? Or because that is how they have been encouraged to greet everyone else? Many people with developmental disabilities have learned *exactly* (concretely) what they were taught, and are then chastised for "inappropriate behavior" by the very people from whom they learned. The power of the abstract world can not be underestimated!

Sometimes a person arrives at a perfectly logical conclusion, but generalized from a different starting point (as Justin did in Chapter two). In other situations, generalizing may not always be easy (as in Brian's case, above).

We need to discover and invent ways to integrate the developmentally disabled person's concrete world with the abstract information and concepts they will need to make their way successfully through the maze of social interactions that make up our world.

Chapter Seven

What Do I Say? How Do I Say It?

Teaching tools and methods

I once showed a slide to a high school-aged class of two people shaking hands. I had intended for it to launch a discussion of meeting strangers, and the mechanics of a simple exchange of pleasantries. One young man saw something very different. He began to tell a story that involved the two hand-shaking people (a woman and a man) and a man in the background of the picture. That man, he said, was a friend of the man in the foreground who had agreed to introduce the couple - the man shaking hands had been wanting to meet this woman for months, and was unsure how to ask her out on a date. Although this was surely not what I had intended, it definitely let me know some of the issues this young man was thinking about!

The following framework will serve to sum up important points to consider when preparing and delivering sexuality and social skills education with people who have developmental disabilities:

- Recognize Feelings
  - Work through consumers' feelings
  - Work with our own feelings
- Utilize a Consumer-Based Curriculum

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Logical versus biological

Be Concrete

Use graduated learning

- Test for Understanding
- Recognize Personal Values

Identify and respect consumers' values

Identify and examine our own values

- Teach Personal, Legal, Social and Medical Responsibility

personal - values, spirituality & religion

social - consent, privacy, law, appropriate/inappropriate, customary social patterns, substance use/abuse

medical - hygiene, disease, pregnancy

- Check the Environment for Inconsistencies

(Adapted from a presentation by Dave Hingsburger, 1994)

Recognize Feelings

The world of human sexuality is vast and diverse. In this society, it is also a highly emotionally charged. Recognize that your audience will likely have a variety of feelings about the subject, ranging from extreme embarrassment to profound curiosity. Remember, too, that approaching this subject will also evoke feelings in you as the presenter, and in other staff you may be training in carrying out the sexuality education program. Be aware of the role of your own past learning and experiences in sexuality. It is also important to be familiar with cultural differences around sexuality, and to consider their roles in your audiences and in yourself.

Consumer-Based Curriculum

Take time to understand the issues that are important to the people you are working with. These issues may or may not be the issues you were called in to address. Remember

the aim of sexuality education to provide accurate, age-appropriate information *in ways that are useful* to your audience.

Approach subjects from a concrete, logical perspective. Take into conside,ation the ways concrete and sequential processing styles may affect understanding of your topics, or your teaching methods. When teaching anatomy and physiology or reproductive matters, first emphasize mastery of the logical steps one must take to be in charge of one's sexual self (menstrual care, safer sex practices, how and when to seek care from a clinician) , rather than the biology underlying them. Activities that recognize this perspective may be as logical as including role playing the steps in making an appointment over the telephone. Or, they may review the ways a person may obtain a tampon or pad when caught off-guard by an unexpected period.

Investigate any steps consumers may have to take that might be different from steps required of others. For example, must consumers notify a staff person in order to seek healthcare or supplies? Do they need assistance in making an appointment? Is there a procedure for securing transportation? How will payment be handled? Be sure to describe and practice these steps with consumers as a component of your program.

Use concrete explanations and graduated learning. Repetition and practice are key, especially with complicated or involved concepts.

Test for Understanding

The presenter can truly be responsive to the needs of the audience only when frequent tests of understanding demonstrate what the audience has learned. This process can be as simple as asking the group to summarize the point just reviewed, or to demonstrate a task or skill recently described. Using feedback in this manner, concepts that are quickly mastered can be briefly covered, leaving more time reserved for those ideas that need further elaboration. The presenter must also be open to the idea that the audience may learn some ideas that were unintended (and have strategies ready to address this possibility).

Recognize personal values

In all sexuality education efforts, it is imperative to identify and respect consumers' values regarding sexuality. In preparing to provide such a program, it is also vital to take time to identify and examine our own values.

Teach personal, legal, social and medical responsibility

The privileges and responsibilities of exploring one's own unique sexuality are multi-dimensional. Personal, legal, medical, and social factors all impact this process. Teaching about the responsibilities associated with one's sexuality is vital.

Personal issues: values, spirituality, religion...

Because sexuality is a highly personal issue, the presenter should give some attention to the role values, spirituality, and religion may play in the lives of their audience, and in their own life. The complex intersections issues of sexuality have with these facets of each individual's personal belief system can profoundly impact the way in which a sexuality education program can be most successful.

Medical issues - hygiene, disease, pregnancy...

Taking responsibility for one's sexual health is another aspect of sexuality that must be emphasized. Awareness and understanding of pregnancy, sexually transmitted disease, and hygiene are all components of sexual health that must be addressed by the sexuality education program. Again, stress pro-active action steps rather than lengthy biological explanations (unless your audience is interested in these).

Legal issues...

The history of sexuality and people who have developmental disabilities is interspersed with the difficulties that many other minority populations have endured at the hands of a dominant culture (for a brief history, see Appendix). But, because the voice of this group has gone largely unheard until recent years, legal quandaries and abuses still remain (particularly with regard to sexual expression). Be aware of the possibility that the

law may be used to treat people who have developmental disabilities differently from any other, group especially in matters of relationships or sexual situations. Recognize that at times may be police are called in to handle a situation that may actually display a consumer's lack of information or curiosity rather than the willful act of breaking the law.

Social issues...

Many ideas and concepts central to sexuality education exist in the context of larger society. Issues of consent, privacy, the law, expected social interactions, and substance use/abuse are somewhat intertwined with some key issues in human sexuality. Understanding ways in which these ideas are interrelated (and especially ways they may differently impact people who have developmental disabilities) forms a necessary foundation for sexuality educators. To adequately provide learning experiences for consumers, we must be cognizant of the societal reality in which we live.

Check the Environment for Inconsistencies

Examine the messages, verbal and non-verbal, that consumers encounter in their living and school/work situations. Evaluate for consistency with the intended messages of the sexuality education program to be presented. If one goal of your program is to encourage appropriate social skills in teen/adult consumers, all aspects of the consumers' life should be consistent with this aim. If consumers are led about by the hand by staff in a child-like fashion during the rest of their day, or encouraged to always hug people in greeting, these would be examples of mixed messages at odds with the skills you are attempting to reinforce.

Likewise, school/agency policy or practice may unwittingly influence the manner in which consumers learn about customary and appropriate interaction. During one training I provided for consumers on the importance of remembering which private bodily functions were not for discussions in public, the unintentional ways in which my sessions were incongruous with real-world practice became painfully clear. Upon visiting the group home where many of my group resided, I noted a huge "menstruation tracking chart" of all the

female residents posted in the main entryway for all the consumers (and indeed everyone who visited the residence) to see. It can sometimes be a difficult and time-consuming process to sort out those practices and policies which are necessary, from those which are merely for the convenience of the staff or are in existence merely because "this is the way it's always been done". Providing suggestions on how required procedures/policies may be carried out in ways which respect the privacy of the consumer while balancing the needs of the organization may also be necessary.

Tips for Application

With this information in mind, this section will begin to brainstorm tools and ideas that may be effective. Although there are some specially made products for teaching about family life and sexuality, there are many everyday items that can be useful as you begin your discussions with your groups.

- Use as many pictures as you can. Photos of family and friends can begin a discussion of relationships and social situations. Even advertisements from magazines can be a springboard for discussion. Begin by asking the group what they see in the picture. What are the people doing? What is their relationship? How do you feel about that? Sometimes, as in the vignette that begins this section, the responses can give you an idea of the important things on their mind at the time. Pictures or slides can also lead to role plays in practicing common social situations such as meeting an acquaintance, asking someone on a date, etc.
- Television shows and videos can also be useful in providing "teachable moments" in family life. If the group does not ask or offer an opinion about a particular plot line, ask them what they think. Remember, you can use both positive and negative TV portrayals to get across your message of both information and exploring values.
- Diagrams or charts of body parts (such as those found in books) can be confusing. Try making a full body chart - use a large sheet or pieces of newsprint. Trace the

outline of the body ahead of time, then use as a visual aid as you discuss internal organs. Or, use the creation of the chart as part of your program - body parts and other features can be drawn in by the participants, and each person can refer to their own customized chart throughout the duration of a unit on sexuality or health. This is a concrete way to show the location of the organs of the body, and provides a backdrop to discuss their functions.

- For more involved tasks (personal care during menstruation, for instance), try to break down the activity into several distinct steps. If you've done this to teach other skills (doing the laundry, taking out the trash, making a peanut butter and jelly sandwich), you can do it with these life skills, too. Review the steps, just as you do in teaching any other activity. Provide feedback and praise.
- As for social interactions - practice! Provide role play situations for participants to perfect their skills (such as shaking hands, having conversations, refusing or avoiding peer pressure, walking away from conflicts). Every opportunity participants have to practice in a safe, supportive environment forms the foundation for success when the real thing presents itself. Striking out into the community for more practice in actual social situations is a essential.
- Don't be afraid to say "I don't know the answer to that question." Be sure to follow up with "Let's find out together". Use repetition with small amounts of information spaced out over time. Ask for feedback so you can check for understanding. Always be prepared with several different approaches.
- Conduct a Sexuality Audit in your classroom, supported residence or agency (see page 76).
- Utilize all the resources you do have. Check out the resources your library has, and refer to bibliographies about talking about sexuality. There are even some videos about people who have developmental disabilities who have achieved their goals of relationships and marriage.
- Network with other providers who serve consumers with disabilities. Offer your insights to others. Be aware of any idea, material, or person that may be a

learning resource for you or your program. And, recognize and validate participant's feelings. This is a unique opportunity to get to know them better!

ⓘ No one approach is best. We are all individuals, with our own unique learning styles. Through this process, you have the opportunity to investigate, experiment, be creative and learn from your mistakes and successes.

As you continue to provide quality care, support and education for people who have developmental disabilities, it is important to continuously evaluate your efforts. What strategies have worked? Which need some refining? What areas would you like more information or education about? Encourage yourself and your agency/organization to proactively assess and evaluate your efforts toward sexuality education and strive toward regularly bettering your work.

Activities, overheads, and handouts

The following pages will provide you with reproducible activities, overheads and handouts to be used in any way you find useful. They follow the order of the information found in Chapters 1 -7, and are labeled on the bottom of each page.

Before each activity worksheet you will find a page describing the goals, materials and procedures for each activity.

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Find Someone Who...

This activity provides an opportunity to start a discussion about sexuality and developmental disabilities. The goal of the activity is highlight the successes and note the challenges participants may have encountered. This activity can serve as a useful tool to gauge the comfort level of your audience when it comes to talking about sexuality issues, while providing an opportunity for the group to informally get to know each other and network.

Materials: Photocopy Activity 1, enough for each person to have their own. Either provide or ask participants to bring their own pencil or pen.

Procedure: Hand out the Find Someone Who activity sheet and give the following directions:
This is a chance for everyone to move around the room and meet people. Your job is to find someone who can answer each of the nine questions on your activity sheet. Each person can only sign their name once on each sheet! You can't sign your own sheet! As soon as you have all nine signatures, please sit down.
(You may want to provide incentives — PRIZES — for the first person to complete their activity sheet.)

Once everyone is sitting again, encourage people to share their experiences: were some questions harder than others, was anyone embarrassed to ask any questions, was anyone surprised by an answer they got?

FIND SOMEONE WHO...

_____ Has ever dealt with issues of determining informed consent with a consumer

_____ Has talked to their parents about sex

_____Has talked about HIV or sexually transmitted infections with a consumer

_____Has talked about HIV or sexually transmitted infections with a friend

_____Had no problem finding accurate information about sexuality when they were growing up

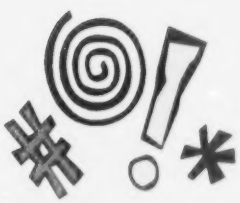
_____Was "drafted" by their agency/school to provide sexuality information to consumers

_____Knows at least two places to find answers to questions about sexuality

_____Knows their agency/school policy regarding sexuality

_____Still has some questions about sexuality

Questions



Feelings

Fears

Overhead 1

Some questions to think about...

Why sex education?

What are my goals?

What are the consumers' goals?

What are my agency's goals?

Overhead 2

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Sexuality Education

must be...

✔ Accurate

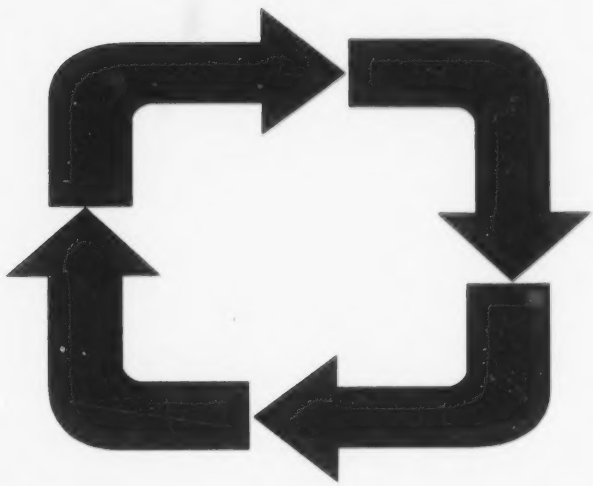
✔ Age-Appropriate

✔ In ways that are useful

Overhead 3

The Traditional Paradigm

seen as
a child



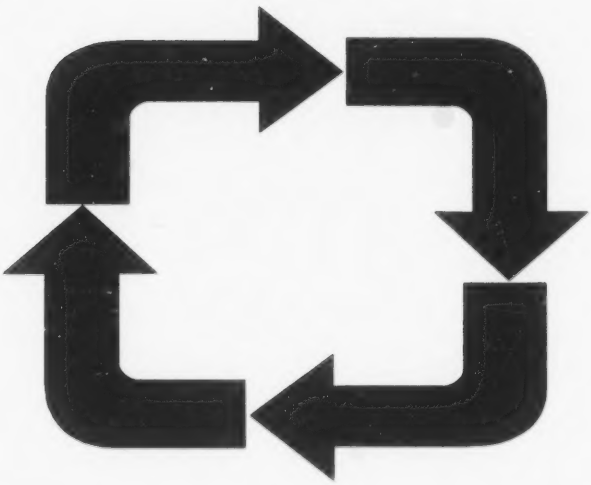
behaves as
a child

treated as
a child

Overhead 4

A NEW Paradigm

seen as
an adult



behaves as
an adult

treated as
an adult

Overhead 5

Why Do I Do This?

The effects of sexuality education are:

✔ Empowerment

✔ Skill building

✔ Learning new information

✔ Communicate

✔ Setting the stage

✔ Articulating goals

✔ Preventing negative outcomes

Overhead 6

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Levels of Comfort

This activity gives participants a chance to think about their personal comfort and the comfort of those around them when discussing the wide range of issues relating to sexuality.

Materials: Photocopy Activity 2, provide enough copies for each person to have their own. Either provide or ask participants to bring their own pencil or pen.

Procedure: Hand out the activity sheet and ask participants to work individually. Allow ample time for them to complete the worksheet — at least 10 minutes.

After they have completed their worksheet, have participants get into groups of two or three. Ask them to process the following questions — remind participants to share only what they feel comfortable sharing:

- ✔ What topics do feel comfortable talking about? Which ones are more challenging?
- ✔ What topics do the people around you feel most comfortable addressing? Which ones are more challenging?
- ✔ Are there any sources of misinformation? Any valuable resources?
- ✔ Is there a pattern...

Levels of Comfort

Everyone is comfortable discussing some things more than others. How do you feel about these topics? How do others — your partner, friends, community —feel about them? Rate how comfortable you feel discussing these issues using the scale of 1 to 5 listed below. Then note how comfortable you think others feel about the same topic. You will not have to defend your answers.

1 = very comfortable
2 = fairly comfortable
3 = neutral or unsure
4 = somewhat uncomfortable
5 = very uncomfortable

	Self	*Partner*	*Friends*	*Community*
Puberty				
Relationships				
Sexuality				
Disability				
HIV/AIDS				
Drug Abuse				
Violence on TV				
Sexuality on TV				
Talking with your kids about sexuality				
Talking with your kids about disability				
Harassment				
Friendships				
Dating				
Physiology				
Emotions				
Touch - appropriate/inappropriate				
Kissing				
Managing Sexual Feelings				
Intercourse				
Abstinence				
Contraception				
Masturbation				
Sexual Orientation				

Values Voting Worksheet

This activity explores the continuum of values surrounding issues of sexuality.

Materials: Photocopy Activity 3, provide enough copies for each person to have their own. Either provide or ask participants to bring their own pencil or pen. Prepare two signs reading: "AGREE" and "DISAGREE" to be used in the second part of this activity.

Procedure: Hand out the activity sheet and ask participants to work individually. Allow ample time for them to complete the worksheet — at least 5 minutes. Ask participants NOT to put their name on their worksheet! While the group is working post the two sings ("AGREE" and "DISAGREE" on opposite sides of the training room).

After participants have completed their worksheet, ask them to crumple it up and throw their paper ball into a pile on the floor. Ask each participant to pick up one paper (being sure they have not chosen their own).

From your master copy, read each statement aloud and ask the group to stand by whichever sign corresponds with the answer on their worksheet (not their own opinion!).

After each statement is read and participants move to the appropriate sign, ask the following questions:

- ✔ what are some reasons a person might agree or disagree with this statement?
- ✔ how might this affect someone's ability to teach or talk about sexuality issues?
- ✔ does the group's position surprise you in any way?

Values Voting Worksheet

Place the letter "A" after each statement that you agree with and the letter "D" after each statement you disagree with. You will not be asked to defend your answers.

1. _____ All people have a right to honest, accurate information about sexuality.

2. _____ Parents have the right to know about their teen's sexual activity.

3. _____ Sexual abstinence until marriage can improve a relationship.

4. _____ Gay and lesbian people should have the right to marry.

5. _____All people should have access to reproductive health care.

6. _____ Consumers deserve the fulfillment of a sexual relationship if they choose.

7. _____ Masturbation is one form of healthy sexual expression.

8. _____ Consumers in intimate relationships should have private time behind closed doors.

9. _____ Latex condoms should be available to consumers in their residences.

10. _____ Providers have a right to know about the sexual behavior of the consumers in their care.

Myth or Fact

This activity discusses the myths and facts about developmental disabilities.

Materials: Photocopy Activity 4, provide enough copies for each person to have their own. Either provide or ask participants to bring their own pencil or pen.

Procedure: Hand out the activity sheet and ask participants to work individually. Allow ample time for them to complete the worksheet — at least 5 minutes.

In a large group, read through each myth or fact, give the correct answer and ask the following questions:

- ✔ what are some beliefs or ideas that support the myths?
- ✔ how can people get more information to increase their knowledge of the facts?

Remind the group to refer to the bottom of their worksheet for one source of information about the facts pertaining to developmental disabilities.

ANSWERS: 1. fact, 2. myth, 3. fact, 4. fact, 5. myth, 6. myth, 7. myth

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Myth or Fact?

1. One out of ten American families are directly affected by mental retardation

2. No people who have developmental disabilities are able to lead fully independent lives

3. In the US, 2.5 to 3 percent of the population have mental retardation

4. Individuals who have neural tube defects such as spina bifida are as prevalent as people who are affected with blindness.

5. Cerebral palsy is a developmental disability that includes lowered intellectual functioning level.

6. The term "mental age" means that one can interact with the person described as if they are in fact that chronological age. For instance, if one has a mental age of 8, their level of functioning and experience is that of an 8 year old.

7. There are three main causes of developmental disabilities

[Adapted from: The Arc, Introduction to Mental Retardation, available at <http://thearc.org/faqs/mrqa.html>]

Definitions

Definition #1: Individuals with Disabilities Education Act (IDEA) of 1990

- Significant Sub-Average IQ

(two or more standard deviations below mean; <70)

- Deficits in Adaptive Learning

- Manifested During the Developmental Period

[Public Law 101-476, Federal Register, 57 (189), Sept. 29, 1992, p. 44801]

Definition #2

American Association on

Mental Retardation

- Significantly Sub-Average Intellectual Functioning
- Limitations in two or more adaptive skills areas:
  - Communication
  - Self-care
  - Home living
  - Social skills
  - Community use
  - Self-direction
  - Health & Safety
  - Functional Academics
  - Leisure
  - Work

[AAMR, 1992, available at <http://www.aamr.org/FAQMentalRetardation.html>]

Overhead 8

Definition # 3

An alternate definition

✔ Developmental disability refers to a level of functioning which requires from society significantly above average training procedures and superior assets in adaptive behavior, manifested throughout life.

✔ The developmentally disabled person is characterized by the level of power needed in the training process required for him/her to learn, and not by limitations in what s/he can learn.

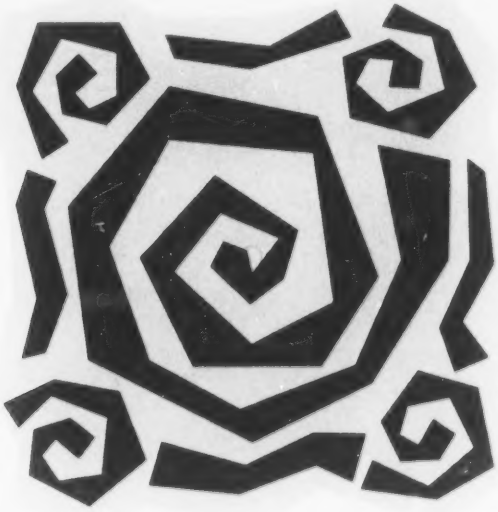
✔ The height of a developmentally disabled person's level of functioning is determined by the availability of training technology and resources society is willing to allocate and not by significant limitations in biological potential.

[Marc Gold, Community Based Residential Services Staff Training Manual, Division of Developmental Disabilities, New Jersey, 1990]

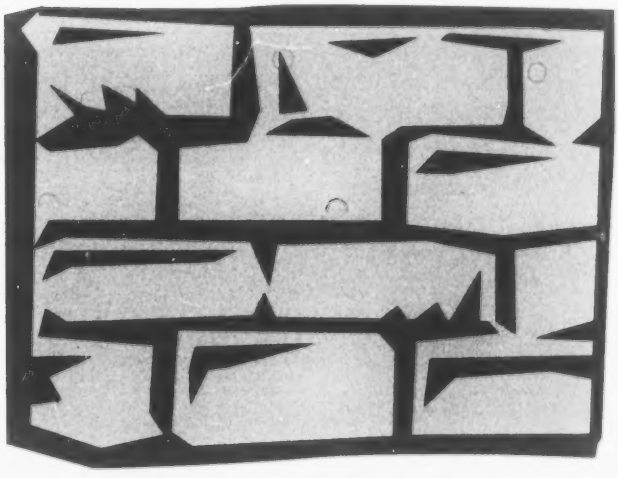
Overhead 9

73

Making Abstract Concepts



More Concrete



Overhead 10

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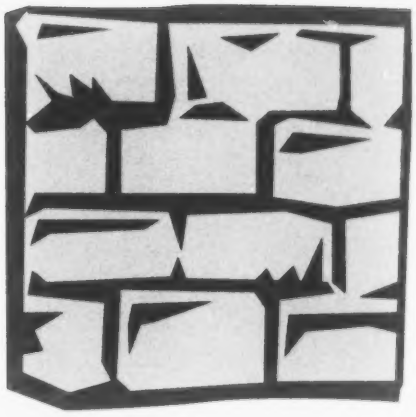
Materials and Information used in Sexuality Education will be most effective if...



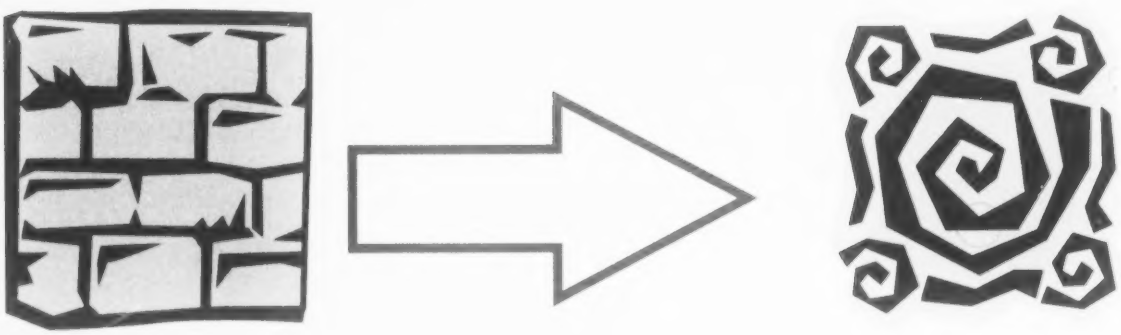
They are accessed in a concrete way

That utilizes all of the available learning channels

Continuums to know about when considering what teaching strategies are best for people who have developmental disabilities

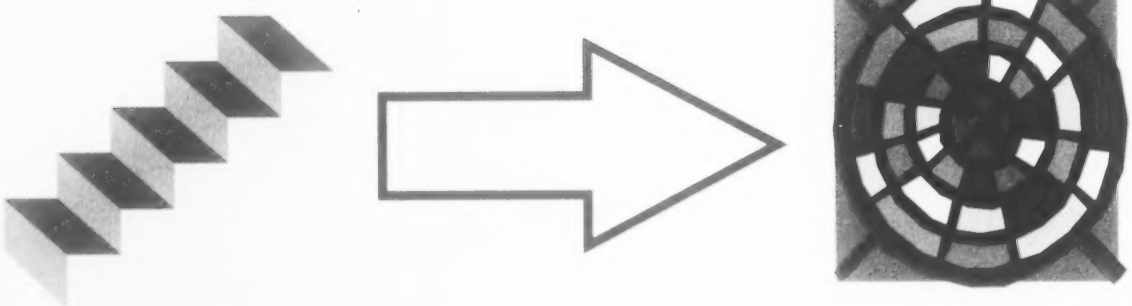
CONCRETE

ABSTRACT



SEQUENTIAL

RANDOM



Overhead 12

Potential Barriers

to effective sexuality education...

Access to/ Availability of Materials

Quality of Materials

Attention Span

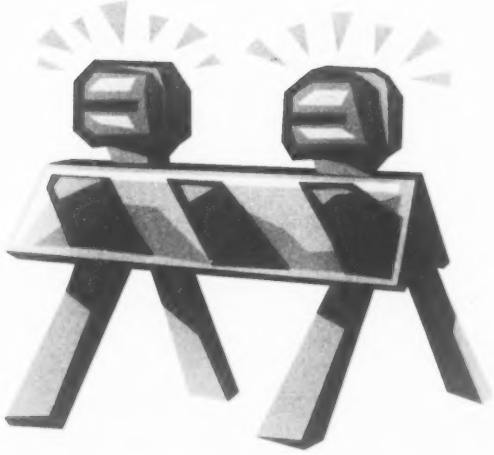
Channels Blocked

Sensing Abilities

Decreased Motor Function

Medication

Other...



Overhead 13

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Other Factors to consider when preparing a sexuality education program for people who have developmental disabilities...

- Past learning
- Present circumstances & relationships
- Future goals
- Societal attitudes
- The law
- Issues of consent

Overhead 14

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Other Factors to consider when preparing a sexuality education program for people who have developmental disabilities...

- ✔ Past learning
- ✔ Present circumstances & relationships
- ✔ Future goals
- ✔ Societal attitudes
- ✔ The law
- ✔ Issues of consent

Overhead 14

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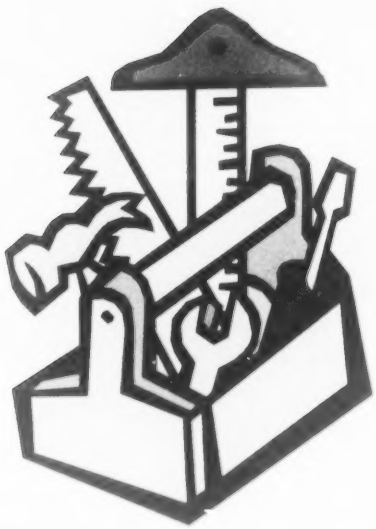
How do we learn what we know?



Adaptive Learning

30

Overhead 15

Some things to consider...

- ✔ Recognize Feelings
  - Work through feelings
  - Work with our own feelings
- ✔ Consumer-Based Curriculum
  - Concrete, logical vs. biological
- ✔ Be Concrete
- ✔ Use graduated learning
- ✔ Test for Understanding
- ✔ Recognize personal values
- ✔ Teach personal, legal, and medical responsibility
  - personal - values, religion & spirituality
  - social - consent, privacy, law, appropriate/inappropriate, customary social patterns, substance use/abuse
  - medical - hygiene, disease, pregnancy
- ✔ Check the Environment for Inconsistencies

[Adapted from Hingsburger, 1994]

Overhead 16

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Sexuality Audit

In order to assure the congruence of positive messages about sexuality, survey the following areas of your professional environment. Asking and getting answers to the following questions can help generate a sexuality education to do list...

Staff Training - Are staff and support people given opportunities to increase their knowledge and skills about sexuality issues? What training materials do you have available for self-study? Do you have a resource center with books, videos or curricula that address issues of sexuality and developmental disability?

Consumer Education - Does your program have staff available who are comfortable being resource people around issues of sexuality if a consumer has a question? Are materials available that lay out sexuality information in ways that are useful and accessible for the consumer?

Living or Recreation Space - What do the posters on the walls and magazines on the coffee table really say to the consumer and staff? Are there positive images of platonic relationships? People holding hands? Are there images of sexual diversity? Are there images that would help encourage discussion about relationships or sexuality issues?

Policies and Paperwork - Do you know the policies your agency or organization has about sexuality? Do you think they are well written? Do they need some help? Can you let the powers that be know your thoughts about the policies? Do your intake forms ask questions about sexual activity or sexuality in appropriate ways?

What would YOU do?

This activity gives people an opportunity to think about and react to scenarios about a variety of sexuality issues and people who have developmental disabilities. The goal of the activity is to give people a chance to practice talking and thinking about these issues before they arise. This will help to build comfort and confidence in dealing with the issues.

Materials: Copy scenarios (Activity #'s 5.1 - 5.8) so each individual or small group will have one topic to discuss.

Procedure: Hand out scenarios to each individual or small group. Explain that they are to read their "HELP!!" scenario and then generate responses for the five questions listed. Allow ample time - no less than 15 minutes to answer the five questions.

Reconvene large group and review the scenarios and responses sharing ideas and experiences. Encourage group discussion about the scenarios — again, the more ease people have in discussing these issues with their colleagues, the more comfort they will have addressing these issues with consumers.

HELP!! Jorge has been caught several times peering into neighbors' windows! He's a pervert - What should we do ??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

→

→

→

→

5. Best Solution/Recommendation?

HELP!! Jules and Lydia insist they will get married someday. How do I make them stop this nonsense??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

→

→

→

→

5. Best Solution/Recommendation?

HELP!! Betty is constantly undressing in public places. We've stopped allowing her to go on outings because of this. What's her problem??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

→

→

→

→

5. Best Solution/Recommendation?

Activity 5.3

Talking Sex! © 1999 Lisa Maurer

Sexuality Education ?? Oh, thank you, but we don't need any here at the Group Home. All our residents are male, and besides, the youngest is 50 years old...

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

→

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5. Best Solution/Recommendation?

HELP!! Maria's parents insist we take her to get that new Norplant contraceptive. Maria doesn't really want it, and after talking with her, it seems she's not sexually active right now and does not want to be in the near future. What do we do??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

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5. Best Solution/Recommendation?

Talking Sex! © 1999 Lisa Maurer

HELP!! Taniesha is so promiscuous - she's always touching men she doesn't know - even in the SUPERMARKET!!! What's wrong with her??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

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5. Best Solution/Recommendation?

HELP!! Tim has just asked about condoms! Where did he hear about them? Is he sexually active? Could he catch some kind of disease, or even worse, spread it to the other consumers or the staff? Who will talk to him about HIV??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

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5. Best Solution/Recommendation?

HELP!! Bob's brother and sister-in-law (his guardians) are really upset - Bob told them about his relationship with Gary (another consumer), and they are convinced Bob is being coerced. Will Gary go to jail? Will I lose my job? Will they sue us??

1. What's Going On?

2. What's Really Going On?

3. Why?

4. What are the next steps you take? (4+ ideas)

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5. Best Solution/Recommendation?

Organizations

Advance - for Occupational Therapy Practitioners, Merion Publications, Inc., 650 Park Avenue, Box 61556, King of Prussia, PA 19406. Provides coverage of news and employment opportunities to therapists nationwide.

American Association on Mental Retardation (AAMR), 444 North Capitol St., Washington, DC 20001-1512. <http://www.aamr.org> An international multidisciplinary association of professionals. Many resources available (most through their website).

The Arc, 500 E Border St., Suite 300, Arlington, TX 76010. <http://www.thearc.org> (formerly Association for Retarded Citizens of the United States) is the country's largest voluntary organization committed to the welfare of all children and adults with mental retardation and their families. Publications include pamphlets and articles (many available through their website), and the video "Russell Talks About AIDS".

Connections, Lane & Laurence, Inc., 28 Parkman Street, Suite #1, Brookline, MA 02146. Written by and for people with disabilities.

Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091, (800) 328-0272. All aspects of the education and development of the disabled and gifted.

Counterpoint, 747 Dresher Road, Suite 500, Dept. 430, P.O. Box 980, Horsham, PA 19044. Published by the National Association of State Directors of Special Education as a service to teachers and administrators of special education.

Dawn Ontario Pamphlets, including *"Women with Disabilities Talk About Sexuality."* 180 Dundas St. W. 210, Toronto, Ontario M5G 1Z8 (416) 598-2488.

Directed Masturbation: An overview of theory and technology presented by Fred Kaeser. Vida Publishing, P.O. Box 331, Willow Street, PA 17584.

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Disabilities Video Collection, Fanlight Productions, 47 Halifax Street, Boston, MA 02130. <http://www.fanlight.com>

Educational Resources Information Center (ERIC), National Library of Education, Office of Education Research and Improvement, US Department of Education. A federally funded nationwide information network designed to provide access to education literature.
AskEric Search
<http://ericir.syr.edu/>
The ERIC Clearinghouse on Disabilities and Gifted Education (ERIC EC)
<http://www.cec.sped.org/ericec.htm>

ETR Associates, P.O. Box 1830, Santa Cruz, CA 95061, 1-800-321-4407. A resource for pamphlets, videos and educational material on sexuality and health.

Families in Society: The Journal of Contemporary Human Services. 11700 W. Lake Park Drive, Milwaukee, WI 53224. A practice- and issues-related journal directed to human service professionals.

National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington DC 20013. <http://www.nichcy.org> An information clearinghouse that provides free information on disabilities and disability-related issues, including articles and state-by-state resource listings available through their website.

Planned Parenthood of Tompkins County, Education & Training Department, 314 W. State Street, Ithaca, NY 14850. (607) 273-1526, ext. 126, <http://www.sextalk.org>. Professional training, consultation, and resources, and *Talking Sex! Practical Approaches & Strategies for Working with People Who Have Developmental Disabilities When the Topic is Sex (1999)*.

Planned Parenthood of Lincoln, Training and Research Institute, 2246 "O" Street, Lincoln, NE 68510. Pamphlet *"We All Have Special Feelings."* A sexual decision making guide for persons with developmental disabilities and those who care about them.

Resourceful Woman, Women with Disabilities Striving Toward Health and Self-Determination, The Health Resource Center for Women with Disabilities, Rehabilitation Institute of Chicago.

Sexuality and Disability. A journal devoted to the psychological and medical aspects of sexuality in rehabilitation and community settings. Human Sciences Press, 233 Spring Street, New York, NY 10013.

Sexuality Information and Education Council of the United States (SIECUS), 130 West 42nd Street, Suite 350, New York, NY 10036-7802, <http://www.siecus.org>, is a national, nonprofit organization which affirms that sexuality is a natural and healthy part of living.

SIECUS develops, collects, and disseminates information, promotes comprehensive education about sexuality, and advocates the right of individuals to make responsible sexual choices. Many resources available (most through their website). See especially *SIECUS Report - Meeting The Needs of People with Developmental Disabilities*, April/May 1995 Volume 21, Number 4, and *Annotated Bibliography - Sexuality and Disability (1995).*

James Stanfield Company, PO Box 41058, Santa Barbara, CA 93140, <http://www.stanfield.com> - A wide array of education and training materials (videos, curriculum, etc.) for students with developmental disabilities grades K-12.

Person To Person, available through American Film & Video, 8901 Walden Road, Silver Spring, MD 20901, (800) 78VIDEO. A video program about the sexuality of persons with developmental disabilities.

Books

A Comprehensive Training Guide for Professionals Helping People with Disabilities that Hinder Learning, Stiggall-Muccigrosso & Davies, 1993

An Easy Guide to Loving Carefully, Stiggall-Muccigrosso, Kempton, and McKee, 1997

A Guide to Consent, Dinerstein, Herr, & O'Sullivan, 1998

I *Contact - Sexuality and People with Developmental Disabilities*, Hinsgburger, 1992

Informed Consent, Sexuality, & People with Developmental Disabilities: Strategies for Professional Decision-Making. L. Griffin, J.D., 1996

Intimate Resources for Persons with Disabilities, Wheeler & Crabtree, n.d..

Managing Inappropriate Sexual Behavior, Alaska Specialized Education and Training Services, 1992.

Mental Retardation - Definition, Classification, and Systems of Support, 9th Edition. AAMR, 1992.

Psychiatry and Mental Retardation: A Curriculum Guide. American Psychiatric Association Committee on Psychiatric Services for Persons with Mental Retardation and Developmental Disabilities, American Psychiatric Association; 1995.

Psychotropic Medication & DD The International Consensus Handbook, Reiss & Aman, 1998

The Rights of People with Mental Disabilities, Levy & Rubenstein, 1996.

Working with Women who Have Mental Retardation, A Genetic Counselor's Guide, B. Finucane, 1998

Websites

Consortium for Citizens with Disabilities - A coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.
<http://www.c-c-d.org/>

Family Village - A global community that integrates information, resources, and communication opportunities on the Internet for persons with mental retardation and other disabilities, for their families, and for those that provide them services and support.
<http://www.familyvillage.wisc.edu/index.htmlx>

Health Promotion and People with Developmental Disabilities - Information on challenging behaviors, general health/well-being, personal care and sexuality.
<http://www.dcs.wisc.edu/pda/hhi/hpp/index.html>

Mental Health Aspects of Developmental Disabilities (MH/DD) A peer-reviewed publication on the diagnosis, treatment, and habilitation needs of persons with developmental disabilities.
<http://www.mhaspectsofdd.com/>

The National Arts and Disability Center - To promote the full inclusion of children and adults with disabilities into the visual and performing arts.
<http://www.dcp.ucla.edu/nadc/>

National Association of Developmental Disabilities Councils
<http://www.igc.apc.org/NADDC>

National Association for Down Syndrome
<http://www.nads.org>

National Association of State Directors of Developmental Disabilities
<http://www.nasddds.com>

The National Down Syndrome Society was established to increase public awareness about Down syndrome; to assist families in addressing the needs of children born with this genetic condition; and to sponsor and encourage scientific research.
<http://research.ndss.org>

National Guardianship Association - to provide educational, training, and networking opportunities for guardians and surrogates; to promote the highest levels of values, standards and ethics; and to ensure a nationally recognized standard of excellence.
<http://www.guardianship.org>

Planned Parenthood Federation of America - a wealth of information about sexuality, including fact sheets on contraception, sexually transmitted diseases and many other topics.
<http://www.plannedparenthood.org>

Prader-Willi Syndrome Association (USA) - A national organization for families, professionals and service providers dedicated to improving the lives of people with Prader-Willi syndrome.
<http://www.pwsausa.org/>

President's Committee on Mental Retardation
<http://www.acf.dhhs.gov/programs/pcmr>

The Sibling Support Project - An excellent site of sibling support resources, workshops and connections regarding brothers and sisters of people with disabilities, chronic illnesses or mental health concerns.
<http://www.chmc.org/departmt/sibsupp/default.htm>

Sites related to cognitive and developmental disabilities
<http://www.waisman.wisc.edu/mrsites.html>

Speaking for Ourselves - self-determination.
<http://www.libertynet.org/speaking/index.html>

Special Child Magazine - Special Child is a free online publication for parents and caregivers of children with special needs.
<http://www.specialchild.com>

TASH - an international advocacy association of people with disabilities, their family members, other advocates, and people who work in the disability field
<http://www.tash.org>

United Cerebral Palsy - Advancing the independence of people with disabilities.
<http://www.ucpa.org/>

Upside - an informal society of individuals, parents, and friends involved with the world of Down Syndrome.
<http://www.telebyte.com/upside/upside.html>

Appendix

Portions of this section originally appeared ***in Positive Approaches: A Sexuality Guide for Teaching Developmentally Disabled Persons,*** *by Lisa Maurer, printed by Planned Parenthood of Delaware, 1991.*

Because persons with developmental disabilities have long been devalued in many cultures, and, at best, considered asexual, resources in sexuality education for this population have been scarce. The following historical review presents an overview of the history of sexuality and developmentally disabled individuals, which illustrates the pressing need for such education. One important fact that underlies this entire subject is that when we attempt to separate sexuality from our lives, we ignore an integral part of that which makes us human. This compartmentalization, so often practiced with those who have developmental disabilities, is a tremendous disservice. By supplying a means by which health care providers, direct care staff, and parents may gain greater understanding of the needs of this population, all of society many be better served.

Historical Overview

The history of society's attitudes toward people who have developmental disabilities does much to illuminate both the underlying attitudes toward diversity and disability, as well as attitudes about sexuality in general.

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Early History

One early reference to people with developmental disabilities is found in a Greek text from 1552 B.C. Individuals with developmental disabilities were referred to as "monsters" in this work (Evans, 1983). Later, in 900 B.C., Lycurgus, the Spartan lawgiver, attempted to assure that Sparta would be kept free of disabled people by mandating their deaths by drowning, abandonment, or being flung from cliffs (Evans, 1983). Time passed, and by 4 B.C. it became a popular practice among the privileged of Rome to "keep" people with developmental disabilities in their homes to entertain guests (Evans, 1983). During this period of time, the developmentally disabled person underwent the transformation from monster to jester, due to society's changes in perception.

People who have developmental disabilities have been viewed from opposite extremes throughout history. During the Renaissance, it was believed that people with developmental disabilities were able to communicate directly with God, while the Reformation labeled developmentally disabled people as satanically possessed. Their "demons" were exorcised through torture or death (Gelb, 1995).

The first medically oriented approach to the treatment of people with developmental disabilities was devised in 1614 by a physician named Montalto (Woolfson, 1984). In addition to Montalto's contribution, he also postulated that his patient's "overindulgence in sexual pleasure" actually caused the disability itself (Rowe & Savage, 1987).

Modern Trends

The Eugenics movement of the early part of this century sought to rid society of imperfect citizens through genetic engineering. Intellectual forces of the time began to advocate proscriptions on marriage and childbearing for people with developmental disabilities due to the fear of overburdening society with the care of disabled offspring (Craft & Craft, 1983). Sterilization became popular as a major method of achieving this end. It would seem however, that mass sterilization as a means of birth control was somewhat

unnecessary, given the fact that segregation of the sexes was rigidly enforced in the institutions of the early part of this century.

During a fifty year period spanning the late 1880s and early 1900s, one particular institution in the US performed 656 castrations on clients in an attempt to stop not procreation, but masturbation. (Russell & Harding, 1980). Similarly, sterilization of women with developmental disabilities was frequently performed, not as a means of stemming the potential for disabled offspring, but as a means of eliminating the need for caregivers and/or developmentally disabled women to deal with menstruation. It appears as though "custodial convenience" was the underlying factor in these sterilization decisions (Rowe & Savage, 1987). Legislation permitting the sterilization of persons with developmental disabilities because widespread in this country. Justice Oliver Wendell Holmes succinctly espoused the reasoning of the times in this judgment:

> It is better for all the world if, instead of waiting to execute degenerate offspring for crimes, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the fallopian tubes...three generations of imbeciles are enough. (Buck vs. Bell, 274 US 200, 1927)

The Mental Deficiency Act of 1913 was Congress' contribution in further legislating the lives of individuals with developmental disabilities. The Act made it illegal for such individuals to marry. The legacy of this legislation pervaded society to such an extent that fully one quarter of the States still prohibited such marriages as late as 1972 (Chinn, Drew, & Logan, 1975).

Gradually, the beliefs that built up this framework restricting the sexual/social lives of persons with developmental disabilities were disputed and broken down. The idea of "routine" sterilization was challenged on many fronts, one of those being an aversion to the striking similarity it shared with the Nazi philosophy of creating a superior people by ridding society of "inferiors" (Gelb, 1995). Still, many people with developmental disabilities were "counseled" to agree to "voluntary" sterilization. Consequently, from 1945 to 1955, 75,000 voluntary sterilizations a year were performed nationwide (Bass, 1979). With laws supporting the notion that developmentally disabled people needed to be protected from society, and society protected from them, it is little wonder that this attitude prevailed (Bernstein, 1970).

Research, however, consistently showed that the ideas upon which these restrictions regarding marriage and reproduction were supposedly based were unfounded. Genetic data alone fails to support mandatory sterilization of all persons with developmental disabilities (Hastings, 1994). Additionally, marriage is a highly important goal among this population (Edgerton, 1967), perhaps because of its portrayal by the media as being what all "normal" people do. Is it a case of society inspecting the lives of such people more carefully, looking for "problems to solve," when the bulk of society may do as it pleases?

Wolfensberger elaborates on this subject:

> There are many nonretarded, physically health
> people who are sex-driven, shallow, incompetent,
> unstable, and incapable of deep, even of
> sustained relationships, yet our political
> system accords them the constitutional right
> to enter a legal marriage...Therefore, we

> should either apply more stringent criteria
> to all citizens, or cease applying them to the
> handicapped...
> (Wolfensberger, 1972).

Concurrently, the notion that persons with developmental disabilities were either sex maniacs or asexual persisted. The Binet IQ test was originally designed specifically to separate the "regular" criminals from those considered "mentally defective," many of them incarcerated for crimes of a sexual nature (Schalock, et al, 1994). In fact, sex offenders with developmental disabilities account for a disproportionately low percentage of all such offenders, and the types of sexual offenses committed by them typically include behaviors that differ in severity as well, such as "voyeurism, exhibitionism, or public masturbation" (Chinn, Drew, & Logan, 1975).

Advocacy groups promoting the rights of people with developmental disabilities began to emerge in the 1950s; the National Association of Parents and Friends of Retarded Children (later, the Association for Retarded Citizens, and now the ARC) is the largest in the country (Evans, 1983). In 1954, the landmark Supreme Court decision Brown vs. the Board of Education, quite unintentionally strengthened the notion of providing the opportunity or equal education to all citizens, including citizens with disabilities (Hastings, 1994). Consequently, the year 1956 marked the institution of coeducational school classes for developmentally disabled pupils (Rowe & Savage, 1987).

The 1960s brought issues facing individuals with developmental disabilities and their families to the forefront of political consciousness, furthered by John F. Kennedy's overwhelming interest in this area (Rowe & Savage, 1987). A declaration of the rights of mentally handicapped people was written in 1968 at an international conference in Jerusalem, and was officially adopted by the United Nations in 1971. Deinstitutionalization, which began in the 1970s, began returning individuals with developmental disabilities to the community, and the ever-existing need for comprehensive sexuality education became more evident.

This considerable change in society's perception of the status of individuals with developmental disabilities appears to be due to two separately emerging trends of that time period. One was the so-called Sexual Revolution, with its corresponding effect on society's attitudes regarding the discussion of sexuality. The second influence was the Civil Rights movement, which broadly viewed, advocated on behalf of many disenfranchised groups' equal protection and services under the law (Craft & Craft, 1983).

But what of fears that the mere provision of sexuality education will "cause" sexual behavior? There is no evidence that sexuality education increases sexual activity in any population *(including the recent World Health Organization study of 1997)*. Specific to the developmentally disabled population, a study by Winifred Kempton (1978), noted educator of people who have developmental disabilities, showed that in a study of 430 students who had participated in sexuality education programs, there were no reports of any inappropriate behaviors in any of the students as a result of the program. In fact, staff working with these students did report significant positive behavioral changes, such as improved social interactions, increased self-esteem, and greater willingness to discuss sensitive issues openly (Kempton, 1978).

Over time, attitudes regarding individuals with developmental disabilities and attitudes regarding sexuality in general have been slow to change. Hopefully, progress will continue to be made on both of these fronts, leading to a better-informed society. Only then can caregivers and other interested friends help to provide the resources and support that people who have developmental disabilities require in learning about and expressing their individual sexuality, thereby obtaining their right to participate fully in the human experience.

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